CANCER HEALTH DISPARITIES

DEBORAH ERWIN, PHD
OBJECTIVES

• Increase understanding of meaning and complexity of cancer disparities

• Increase understanding of efforts to study and eliminate these disparities
DISPARITIES

Public Health Definition ...
Defined as “observed clinically and statistically significant differences in health outcomes or health care use between socially distinct vulnerable and less vulnerable populations that are not explained by the effects of selection bias”

DISPARITIES

Differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the U.S.
DEMOGRAPHICS OF WNY

• 8-county area of WNY 1.5 million
  • 18% non-white/minority
  • 10% African American

• Erie County 919,040
  • 22% non-white/minority
  • 13% African American
  • 4% Hispanic

• Buffalo 261,310
  • 50% non-white/minority
  • 39% African American
  • Hispanic, Mixed race/ethnicity
Although population of Buffalo and Erie County may have small amount of pop decline...

- 23% increase in minority populations 2000-2010
  - Hispanic: 36% increase
  - Asian: 30% increase
  - Native American: 9% increase
  - African American: 6% increase
  - Mixed: 19,819
DEMOGRAPHICS OF WNY

- 8-county area: 12.4% below poverty
- Erie County: 13% below poverty
- Niagara Falls: 16% below poverty
- Buffalo: 27% below poverty
Goal:
To assure that all cancer patients in Western New York can benefit from the clinical and scientific advances accomplished at Roswell Park Cancer Institute.
MEASURES FOR ASSESSING DISPARITIES & PATIENT DIVERSITY

- Race/ethnicity
- Age
- Geographic location
- Insurance status
- Income (not available in EMR)
- Education (not available in EMR)
OVERVIEW OF DISPARITIES IN CANCER

- Blacks/African Americans more likely *to be diagnosed* with cancer
- Age-adjusted total cancer mortality is higher in Blacks/African Americans*
- Blacks/African Americans less likely* to be diagnosed with early stage cancer
- Blacks/African Americans less likely to survive five years or longer*
- Disparities in most screening rates (exception – Pap)

* As compared to Whites

*Age-adjusted to the 2000 US standard population.

Data Source: Surveillance, Epidemiology, and End Results (SEER) Program, 1975-2003, Division of Cancer Control and Population Sciences, National Cancer Institute, 2006.
BREAST CANCER INCIDENCE RATES BY RACE AND AGE

Source: SEER 1996–2001
Note: Graphs may not begin at age 20 due to sample size limitations.
THE CHALLENGES OF ELIMINATING DISPARITIES

• Socioeconomic Status (SES) & Poverty

• Race/Ethnicity (e.g., “The Color Line”)

• Social Context of SES, Color/Race & Health
CHALLENGES – SOCIOECONOMIC STATUS (SES) & POVERTY

• Chicken v. Egg
  • Poverty → health disparities
  • Poor health leads to higher med $ & reduction of work → poverty

• Proportional poverty
• Wealth...
CHALLENGES – RACE

• Race is frequently used

1. “...uncritically as a proxy for unspecified genetic, sociocultural, or behavioral risk factors.” (Gravlee, Non, Mulligan 2009)

2. “...studies that do test specific genetic or sociocultural hypotheses seldom test competing explanations” (Gravlee, Non, Mulligan 2009)
CHALLENGES – RACE

• Social justice issues
  • Social prejudice & racism (e.g., religion, new immigrants, minorities)

• Race & Health 1933-1999 (Levine et al Pub Health Rep 2001)
CHALLENGES – SOCIAL CONTEXT OF SES & RACE

• Racial residential segregation & health
  • Higher cost for housing, food, insurance, etc
  • Poorer quality grocery items → poorer nutrition
  • Targeted for tobacco and alcohol products
• Discrimination & Medical Mistrust
• Must move beyond biomedical model (focus on disease and individual risk behaviors)
  • Pathways for how we “embody” SES & Race
  • “How Race Becomes Biology…” (Gravlee 2009)
HEALTH DISPARITIES: LOOKING AT MULTIPLE FACTORS

- Genetics
- Health Behaviors
- Social Determinants
MULTIPLE FACTORS ➔ DISPARITIES “UNNATURAL CAUSES”

• Is Inequality Making Us Sick?
  • [http://www.youtube.com/watch?v=diMVgcb8Qzk](http://www.youtube.com/watch?v=diMVgcb8Qzk)
HOW CAN RESEARCH HELP TO ELIMINATE HEALTH DISPARITIES?

• Issues to consider:
  • Health is complex
  • People are complex

• Consider context:
  • Environment: Physical and Social
    • Within the social environment some will engage in normative behaviors that can influence health in various ways
  • Cultures exist within every society, group, place or time and are not always considered comprehensively in biomedical research
DEFINING CULTURAL COMPETENCE

...is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge and skills along the cultural competence continuum.

-(adapted from Cross et al., 1989)
ORGANIZATION REQUIREMENTS

- Reflected in the:
  - Values and principles
  - Demonstrate in behaviors and attitudes
  - Policies and structures

- Have the capacity to:
  - value diversity
  - conduct self-assessment
  - manage the dynamics of difference
  - acquire and institutionalize cultural knowledge
  - adapt to diversity and the cultural contexts of communities they serve
CONSTRUCT LIMITATIONS

- Ongoing debate on how to better define and operationalize cultural competency

- Additional terms proposed to capture the meaning: cultural sensitivity, responsiveness, effectiveness, proficiency, and humility

- Models for operationalizing cultural competence often emphasize particular aspects of the health care system, especially the provider-patient interaction
COMMUNITY COMPETENCE

❖ Evolves from perspectives related to cultural competence

❖ More focused approach that reaches deeper into the population at risk with a core focus on applications

❖ Populations can be heterogeneous and are composed of more than the sum of their culture

❖ Compatible with capacity-building construct because it is a problem solving tool that is organically intertwined with local culture and values  
  (Hawe & Shiell, 2000)
COMMUNITY COMPETENCE: PRIMARY CONSTRUCTS

- History
- Culture
- Geography
- Context
COMMUNITY COMPETENCE: PRIMARY CONSTRUCTS

- History captures the important phenomena that have shaped the collective consciousness of a people

- Culture includes the values, norms, faiths, and beliefs that inform the behaviors and collective lifestyles of a people

- Context is the current reality that confronts a people

- Geography provides an ecologic mechanism for distinguishing within and across populations

(Robinson, 2005)
COMMUNITY COMPETENCE: SECONDARY CONSTRUCTS

- Language
- Literacy
- Multigenerational appeal
- Positive and salient imagery
- Diversity
• Provision of language interpreter services (Chang & Fortier, 1998)

• Developing low literacy materials also has proven to be effective (Jacobson et al, 1999)

• Positive imagery reflects the strengths and assets of a population and salient imagery focuses on those images that are particularly effective within a population
COMMUNITY COMPETENCE: SECONDARY CONSTRUCTS

- Multigenerational approach ensures that interventions will not overlook the potential importance of targeting more than one generation or stressing the importance of one generation as an important reason for behavior change among adults

- Diversity encompasses a range of race/ethnicity and other sociodemographic (i.e., rural/urban, poverty) variability contained within a population, including gender orientation

(Robinson, 2005)
## COMPARISON OF CONSTRUCTS

<table>
<thead>
<tr>
<th>Cultural Competence</th>
<th>Community Competence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Best utilized when critical focus is the individual</td>
<td>Improves in saliency the higher the level of aggregation in the population being addressed</td>
</tr>
<tr>
<td>Applied as a management tool for diversity and a guideline for program development</td>
<td>Cultural competence is one of many significant facets in this model</td>
</tr>
<tr>
<td>Often takes on a reductionist approach</td>
<td>More comprehensive and broad-based approach to addressing health disparities</td>
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</table>
DISPARITIES INTERVENTIONS & RESEARCH

HOW TO REDUCE DISPARITIES
BREAST CANCER & AFRICAN AMERICAN/BLACK WOMEN

• Although the incidence of breast cancer is lower among black women than white women, black females have higher mortality and lower five-year relative survival

• Breast cancer in black women is less likely to be diagnosed in the local stage compared with white women

• Five-year relative survival rates are approximately ten percentage points lower for black women than for white women in each age group
In church, people witness to save souls.
At the Witness Project, they witness to save lives.
• Culturally competent…
  • Survivors (credible messengers)
  • Telling their stories (meaningful messages – Narrative communication)
  • Within a spiritual context (credible and meaningful environment)
THE WITNESS PROJECT®

• Increase breast self-examination (BSE)
• Increase mammograms
• Increase clinical breast exams
• Increase Pap tests
• Decrease disparities in cancer morbidity and mortality in African American women


BREAST & CERVICAL CANCER DISPARITIES FOR LATINAS

- Use of Mammography
  - Latinas*  59.6%
  - NL Whites  68.1%

- Use of Pap tests
  - Latinas*  74.6%
  - NL Whites  81.4%

*Latinas – aggregated as a single racial/ethnic group
## BREAST & CERVICAL CANCER DISPARITIES FOR LATINAS

- **Use of Mammography**
  - Mexicans: 59.4%
  - Cubans: 68.4%
  - Puerto Ricans: 72.5%
  - “Other”: 68.5%
- NL White: 68.1%

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ESPERANZA Y VIDA (HOPE & LIFE)

- Community-based intervention
- Cancer survivor role model
- Navigation to screening services
- Goal: Investigate effectiveness of Esperanza y Vida for increasing breast and cervical cancer screening compared to control (diabetes)
Methods

- Randomized Interventions
  - Cancer v. Diabetes
- Program sites (churches, homes, community org’s)
  - Arkansas (AR) (Mexico)
  - New York City (NYC) (Diverse)
  - Buffalo (WNY) (Puerto Rico)
- Audience Response System (ARS) data collection
- 2-month follow-up (educational program alone)
- 8-month telephone follow-up (with navigation)
- Focus on newer immigrants, Spanish-speaking, lower income
RESULTS

• Cancer knowledge did not enhance screening

Influential factors for Mammography & Pap:

• Outreach to women in the community & how to access the system (navigation)

• Navigators ➔ cultural brokers (cognitive & sociopolitical factors)

• NY sites/Puerto Rican women most likely to be screened (higher bl screening)

• Negative impact of sociopolitical conservatism in the South

• Prior screening experiences
DISPARITIES & LUNG CANCER
LUNG CANCER

- **Lung cancer incidence**
  - African American men: 112 per 100,000
  - White men: 82 per 100,000

- **Lung cancer incidence in WNY**
  - African American men: 97.4 per 100,000
  - White men: 75.4 per 100,000

- **Lung cancer mortality rate WNY**
  - African Americans: 80.8 per 100,000
  - Whites: 58.0 per 100,000
LUNG CANCER

• High Risk Lung Cancer Clinic at RPCI
  • Spiral CT scan
  • Bronchoscopy
  • Removal of lesions
  • Tissue samples, surveys, etc → Stacy Scott Lung Ca Registry

• Stacy Scott Registry
  • >400 patients
  • Only 4% were African American

Initiated a pilot to address these disparities
LUNG CANCER - RESULTS

• Fire Fighter Recruitment
  • N=332

• Community Recruitment
  • N= 164

Total N= 496

• 19.2% African American
• 16.3% Native American
• 50% Males ages 40-59
• 21.2% High school graduates
• 127/496 (25.6%) former smokers
• 61/496 (12.3%) current smokers
LUNG CANCER - DISCUSSION

- Minority patients were proportionately responsive (If asked, pts respond…)

- Calculating Return on Investment (ROI) for RPCI for a clinical program …

- Demonstrated ability to double minority patient accruals in about 12 weeks with focused outreach
RESEARCH PARTICIPATION

With YOUR help, we can find the Answers!

Family and Friends of Patients

In a short amount of time, you can make an important donation to cancer research. By giving a small blood sample and by completing a questionnaire, you are helping us to find the answers to cancer.

Roswell Park researchers rely on samples and data from people like you – those over the age of 18 without a personal history of cancer – to discover what causes cancer and how to cure it at an early stage.

Visit the Information Desk or call 716-845-7774 to set up a time now to participate or make an appointment for a more convenient time.

Ask Us About the Data Bank and BioRepository
at Roswell Park
716-845-7774
Email: dbbr@roswellpark.org
www.roswellpark.org/dbbr
RESEARCH PARTICIPATION - RESULTS

- 1-hour program (n= 97)
- Health fair event (n=56)
- Total N= 153
- 114/153 (74.5%) consented to biobanking study
  - 111 (73%) donated blood
  - 13 (8%) donated saliva
  - 80 (52%) completed 36-page lifestyle survey
- Of 97 education program participants, 59 (61%) donated specimens
- If phlebotomist was on-site, 91% of potential participants donate
RESEARCH PARTICIPATION - DISCUSSION

- Participation was higher for blood donation than epi survey.
- Actual participation was higher than reported willingness to participate by a separate community survey (75% v. 61% -survey; 39% -blood).
- Niagara Falls & Love Canal....
- Lack of trust in pharmaceutical companies.

We developed a second study to assess responses to biobanking by Hispanic/Latino populations... “Hoy y Mañana”
DISCOVERING METHODS TO RECRUIT AFRICAN AMERICAN WOMEN INTO RESEARCH

Help us find the Jewels in our GENES a family study
DISCOVERING METHODS TO RECRUIT AFRICAN AMERICAN WOMEN INTO RESEARCH - BACKGROUND

- $BRCA1/2$ genetic discoveries - 20 years ago
- Research with over 329 women from 23 extended families who volunteered genetic specimens
- 96% of BRCA mutation carriers are white

Why have we not explored inherited genetic links for breast cancer in women of color....?

African American and Black women in the U.S.
- higher incidence of pre-menopausal breast cancer
- higher breast cancer mortality rates than white women
THE BALANCING ACT OF GENETIC RESEARCH & “PERSONALIZED MEDICINE”
THE RESEARCH QUESTION

• An African American woman in Buffalo, NY (Veronica) asked me, “Why? What is the gene that is affecting MY family?”

From right: Evelyn, Veronica and Mary
GOAL & AIMS

Genome-wide linkage analysis: “Search for novel breast cancer susceptibility genes in pedigrees of African ancestry” (“Jewels in Our Genes”)

• Recruit at least 125 relative pairs (i.e., families) with at least two women with breast cancer from each family,
• Older unaffected women from the family
• Total of at least 250 cases and 86 unaffected relatives
• N= 336 African American women

1. Partnership with National Witness Project (outreach & screening for breast & cervical ca)
2. Letters to black women who had participated in other epidemiological studies on breast ca
3. Face-to-Face, National conferences & Meetings (e.g., Sisters Network; Komen races)
4. Susan Love/Avon/Army of Women (AOW) website (e-blasts)
   • Telephone follow-up ..... For all of the above...
2009-2012
• Total of 342 African American women
• Affected by breast cancer (n=248) and
• Unaffected (n=94) siblings from
• 127 families completed biological donations and surveys
## RESULTS: WOMEN RESPONDING TO RECRUITMENT BY APPROACH

<table>
<thead>
<tr>
<th>Outcome</th>
<th>National Witness Project*</th>
<th>Letters to participants in other epidemiology studies</th>
<th>Avon/Army of Women Internet E-blasts</th>
<th>Face-to-Face National Conferences**</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>All women who responded or were contacted (&quot;total pool&quot;)</td>
<td>118</td>
<td>220</td>
<td>272</td>
<td>61</td>
<td>671</td>
</tr>
<tr>
<td>Determined to be ineligible</td>
<td>3</td>
<td>81</td>
<td>65</td>
<td>4</td>
<td>153 (23%)</td>
</tr>
<tr>
<td>Refusals</td>
<td>4</td>
<td>15</td>
<td>9</td>
<td>2</td>
<td>30 (5%)</td>
</tr>
<tr>
<td>Outstanding</td>
<td>5</td>
<td>8</td>
<td>17</td>
<td>6</td>
<td>36 (5%)</td>
</tr>
<tr>
<td>Unable to contact or unresolved at close of study</td>
<td>11</td>
<td>34</td>
<td>65</td>
<td>0</td>
<td>110 (16%)</td>
</tr>
<tr>
<td>Complete</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- affected</td>
<td>70</td>
<td>57</td>
<td>87</td>
<td>34</td>
<td>248</td>
</tr>
<tr>
<td>- unaffected</td>
<td>25</td>
<td>25</td>
<td>29</td>
<td>15</td>
<td>94</td>
</tr>
<tr>
<td>Total recruited</td>
<td>95</td>
<td>82</td>
<td>116</td>
<td>49</td>
<td>342</td>
</tr>
<tr>
<td>% Yield</td>
<td>81%</td>
<td>37%</td>
<td>43%</td>
<td>80%</td>
<td>51%</td>
</tr>
</tbody>
</table>

*Includes recruitment by sites and from site visits

**Face-to-Face & National Meetings other than National Witness Project, but staffed by Witness Project
JEWELS IN OUR GENES
DISCUSSION - CHALLENGES

• Process took an extra year
• Challenges for National Witness Project teams
• Funding for “recruitment” – not an afterthought (e.g., travel, hiring race/culture-concordant staff, “tchotchkes”)
• Communication & perception challenges among community members and academic researchers & role of anthropologist (broker)
JEWELS IN OUR GENES
DISCUSSION - SUCCESSES

• Effectiveness of community-based participatory research (CBPR) & collaboration
• Internet can be cost-effective, especially for younger women
• Face-to-face and appropriate telephone contacts – Essential
• Needed multiple methods, reaching women at multiple levels

“It takes a village…”
NEXT STEPS:
THE CENTER FOR PERSONALIZED MEDICINE
SUMMARY …

• Importance of cultural tailoring and approach

• Sensitivity to variations in communities – importance of LOCAL culture

• Messaging and communication is sensitive to minor racial/ethnic/gender/age/geographic variations

• Importance of direct education & communication for low literacy, language challenged sub-groups
...SUMMARY

• Appropriate methods are time & labor intensive

• Medical mistrust, compliance issues, resistance to participation are based on experience(s)

• Inequities are a systems problem not a patient problem – Don’t blame the victim!
ACKNOWLEDGEMENTS – WITNESS PROJECT

- The National Witness Project Steering Committee
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QUESTIONS?